

# Voicesfor Change

Issue #26

A Statewide Newsletteer of the Mental Health Community

Spring 2009



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## Special Issue: Would you go to the Hospital or not?

In this Summer Issue, we decided to pose a question to our readers (as many of them as we could reach) a question about their mental health care: *If you needed intensive mental health care, would you go to a mental hospital or psychiatric ward? Why or Why Not? Would you take care of yourself some other way? How?* This idea came to us from Kimberley Warsett and Sara Sternberg. We have had a variety of interesting responses that we would like to share and we welcome your responses on the Lived Experience Forum [lemforum.org](http://lemforum.org) or to the editor [susan.landy@verizon.net](mailto:susan.landy@verizon.net) .



Taunton State Hospital

## My Vision of a Hospital

By Chaya Grossberg

If I were to have a breakdown and become in need of intensive care, I would not go to most of the hospitals that exist in this country. In my experience, hospitals have always forced or coerced me onto many unwanted drugs that

destroyed my health, but made me tired and apathetic, so I could be easily controlled. Also, the hospital environments were loud, stressful, populated with very unhealthy, highly drugged

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## Transformation Center Mission:

As peers in all stages of recovering our mental health wellness and freedom from addictions

We promote the growth and voices of people with lived experience, individually, in communities and in organizations.

We facilitate these diverse voices to impact and transform policy and practice.



Chaya Grossberg

## A Vision

(Continued from page 1)

and traumatized people and staff were disinterested in much but control of the environment. The food was sometimes unhealthy, although, in a crisis, it is nice to have food and snacks prepared for you.

That said, I would like to go to a hospital, perhaps, if it were a very different kind of hospital. One where there were many options for treatment, none forced, but all available, with information on the treatment potentials, underlying theories, and risks, if any, all easily accessible. I would go to a hospital that offered: lots of time in nature, fresh food of very high nutritional value, meditation groups, writing groups, art groups, one-on-one talks with kind, loving counselors who are spiritually oriented, massage, yoga and exercise opportunities, acupuncture, nutritional counseling with supplements available, herbalist consultations with herbal preparations available, prayer groups, and quiet time to rest whenever needed. I would go to a hospital where others who have been through a breakdown/extreme states/trauma/spiritual transformation and now living highly healthy lives were much of the staff. I would go to a hospital that of course let me talk to friends and family on the phone and have visitors. I would go to a hospital that I

could check out of when I felt ready.

So my answer is no and yes. A hospital should be truly hospitable and offer a variety of options designed to help, increase deep health and treat in ways that are nurturing, patient and honest. I would also like to be in a beautiful environment with inspiring art, poetry, music and options for quiet time alone too.

## I have a Voice

By Ellen Macozek

I still struggle at different times with my life and my thoughts and beliefs and have to do a lot of reality checking and sole searching to accept extra support from my providers. When I start to struggle more with my condition I may even try to work part-time for a couple of weeks and attend a partial hospital program which has helped in the past. I work very closely with the prescriber of my medications. It is very different now for me as opposed to the past because it used to be that I would end up in the hospital for everything and anything. This was because of my lack of skills or knowing how to deal with certain situations and I literally had no voice to speak up to anybody.

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# Poem

By Christopher Magnussen

Step out of your own blind spot, idolize your self.  
See the rippling water, way below.  
Pray before you leap, this water just may be deep.

Rise above the surface, dripping wet with light.  
Step out of your own blind spot, idolize your self.  
Blonds, reds, blues, blacks and the other colors too.  
Rise above the surface, dripping wet with light.  
Step out of your own blind spot, idolize your self.

Step back into your own blind spot, and disappear.



Christopher Magnussen

## I have a Voice

(Continued from page 2)

I try very hard to stay away from intensive hospitalization treatment, not because it is all that bad for me but I need to know that I've done everything I could possibly do to help myself before making the decision to go inpatient. Not to say it's an easy decision, it actually becomes more

and more difficult as the years go on because I feel like a failure. I eventually realize on my own and with some assistance that it's something I needed at the time to break the cycle of what is happening with me at that moment in my life. I kind of look at it like, "Okay, this what I need to do for very short term," and try to remind myself that this is just my tune up so I can go out and continue to live a productive life. This is as well as a way of me keeping my self in check so I can leave the hospital and go back to work and my life which is so important to me. It's a way of me keeping my engine going and seeing it as general maintenance on my mental health. By far it's been an extremely difficult decision and I go back and forth in my head should I or shouldn't I. I know that when I ultimately do make the decision it is the right one for me. Again, the difference for me is that it ends up being my decision and on my own terms. I realize I've done everything I could and then finally give into myself. I say, "Self, don't be so stubborn," and go get what I need and tell myself that it's okay to get some extra support at that time with constant reminders that hospitals and doctors do not rule my life – I rule my own life. "I Have A Voice." I am no longer live life mute.

This is only my personal opinion and I understand how some consumers are totally against any kind of hospitalizations and all power to them if they can rally from a hard time or situation. Again, it's my personal

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# I have a Voice

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choice and not an easy one but in the end I need to leave the past in the past and remind myself that extra help is there for me in case I need or want it.

If you would like to read the complete article, please go to [www.transformation-center.org/news/newsletter/vfc.html](http://www.transformation-center.org/news/newsletter/vfc.html)

## The Help is There

By Jeff Rothman

My name is Jeff Rothman and I am a peer specialist at the Southeast MA Recovery Learning Community. I was diagnosed with bipolar disorder in September of 1992 following a pattern of bizarre behavior. I have survived numerous suicide attempts and am a living and breathing testimony to the power and strength of recovery.

I have mixed feelings when addressing the question of whether or not I would go to a hospital if I needed intensive mental health care. If I focus on the dreadful, painful experiences I've had at psychiatric hospitals, the answer is easy. A resounding never again!

I had to endure horrifying cir-

cumstances during my many psychiatric commitments, some of which can't be detailed here because it's too graphic or triggering. I can say that being put in restraints and almost wrongfully injected with insulin are two events that are high on my list of why I would not want to go back to a hospital. Having said that, I know that when I've been in acute crisis, I wasn't capable of taking care of myself. That's often the case with bipolar disorder when mania strikes.

I'll be honest. I've never been a fan of psychiatric hospitals. They're simply unpleasant places to end up in. I should know. I've been committed 10 times. I do concede that there are some staff at these hospitals who are supportive, caring people who tried to make life less miserable for me. Misery was a common thread among the patients I was in the hospital with. No one wanted to be there, to suffer the loss of our freedom and live in such an unhealthy atmosphere. However, as clichéd as it is, necessity is the mother of invention.

If there was some other way I could have taken care of myself, I would have. I stayed compliant with my medication, but my illness demanded to be heard. I don't see how I could have avoided the hospital. That's not to say that a hospital

has to be the route everyone takes. It just was the case for me. I believe there are degrees of mental illness, each case different from the next.

It's been several years since my last hospitalization. Looking back, I try to remember some of the good people I met over the years and the help I received. I'm grateful to have my life back. I wish the same for anyone else coping with a mental health diagnosis. The help is there. It just takes some time to find it.

## OK Alone

By Timothy Lee

This is a hard question to answer, because when I am having severe symptoms, that would be the only time I would need to go to the hospital. My diagnosis is paranoid schizophrenia, and severe symp-

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# OK Alone

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toms for me happens when I go off my med. I'm lucky that I only need a small dose, and only take one, but I still need to take it. I learned that the hard way, trying to go without it, and I invariably develop symptoms of paranoia, visual and auditory hallucinations. When I'm doing all right, I sometimes laugh at some of the thoughts I had. But I know that when I have symptoms, it "makes sense" at the time to me, although not to other people.

Generally, I'm a homebody, and do a lot of reading, from books and on the Internet. I like to do my own research about my mental illness, and on other topics I have questions about, so I read a variety of nonfiction. I would rather draw my own conclusions and set my own direction, rather than have someone else do it for me. It's not that therapists and social workers are not helpful, but I have often had lots of questions that were not answered to my satisfaction, that I needed to do more research and study on my own. The therapists and doctors have other patients to see, and can't devote all their time to my numerous concerns, so I've learned more by making and going my own way.

I never did feel that I fit into hospital routines very well. For instance, I like to do things independently, and questioned why "isolation" was necessarily

a bad thing. I've learned and done lots of things in my life alone. Sometimes, people say that they're no good alone, that they need someone like a best friend or spouse, but I've always been OK alone. Not that I don't have any friends or never had a girlfriend, but I also do quite well alone, something that my community support worker still has a hard time understanding.



Timothy Lee

## Alternatives to Hospital

By Amy Manion

I've actually had to consider this question because I'm a transitional age youth (kind of over the hump, if you ask me) who is in transitional housing. In order to receive this housing, I needed to fill out paperwork regarding what I'd like to happen to me in case of a crisis. I immediately knew of the hospital I did not want to go to (only been to 2 and a half). Then I thought, I didn't like any of them. Brock-

ton wasn't that bad. This was because most people were in better mental shape than the Arbour where I stayed afterward. Quincy Medical Center was fine because I had a lot of privacy. Arbour Hospital in Jamaica Plain I'd never want to go back to. I felt I had no voice or privacy. I felt I had no say in my treatment. I was attended to by orderlies and nurses – not mental health professionals.

Truth be told, I don't think any one wants to go to the hospital. There is a place in Somerville called the Ruby Rogers Center at 64 Union Sq in Somerville, 02143. For more information about the Ruby Rogers Center, Please contact George Enos, Program Director, at (617) 625-9933 . The Ruby Rogers Center is open to those at risk for psych hospitalization or welcoming to people after psychiatric hospitalization to help reintegrate into the community. It is run by psych survivors and it's open six days a week (not Saturday) from 10am until 4pm. What about if a crisis situation needs to be dealt with outside of those times? Could a person's family and the person herself hold off until that time?

If this happens, there is a Crisis team at SSMH

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# Alternatives

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which offers short-term overnight stays. Granted, this could probably be isolating and I heard it was a weird experience. Truth be told, no alternative will probably be comfortable. I know of someone who was going to go to Psych hospital as they had done many times before but received spiritual intervention from a religious leader. I find spiritual leadership is very important. I know of someone who's a Wiccan and says that helps her. To each their own I guess.

The reason I don't want to go back to hospital may be two-fold. First of all, I was in really bad shape during those times. Also, I felt that being around others in bad shape made it worse. I don't feel comfortable rooming with a stranger, not having freedom, not even being able to have a weekly therapy session (unless you call the group therapy therapy). I guess in some ways it was helpful but I didn't always want to speak in front of everyone else. I think being diagnosed with social anxiety a while back had something to do with my discomfort.

Other ways I'd take care of myself, would be like I said earlier: go to Ruby

Rogers Drop-in Center, SSMH Crisis Team, then probably Mclean or SSMH inpatient if absolutely necessary. Perhaps before all this, I'd call my therapist, housing counselor, and Pastor and other spiritual leaders in my church and or the Messianic temple I occasionally go to. I would also talk to a Peer Counselor or someone from TRACS (Transition Resources and Community Supports) program at Quincy Mental Health Center. The TRACS program is for young adults. I want to get an Advance Directive completed ASAP so I will go to the place I want to go to. You just feel so powerless. A Psychiatric Advance Directive can shorten the hospital stay, ensure you have what you want stated, and things like that. However, it is not legally binding. I might try and see where I can go related to the [freedom-center.org](http://freedom-center.org) which is an alternative to the Psychiatric system.

For the complete text of this article, please go to [www.transformation-center.org/news/newsletter/vfc.html](http://www.transformation-center.org/news/newsletter/vfc.html) .

If you wish to comment directly to the author, she can be reached at [amy.manion@gmail.com](mailto:amy.manion@gmail.com)

# Trapped

By Amy Warsett

Nothing can stop a mania like your first time being locked up. At least that was part of this fifteen-year-old's experience.

Right before I blew out sixteen candles, surrounded by my family who knew my life and theirs had taken a drastic turn, they chose to put me in the children and youth's unit of one of the purported best mental hospitals in the country, smack in the middle of the happening Topeka Kansas.

It was surrounded by quiet lawns to take a walk around with a mustached older doctor and had a playground to play on or in my case to look out at with my hands pressed against my bedroom window while I was not allowed to join the other kids outside.

Upon arrival, a social worker with a long skirt, (it seemed like all of the women working there wore skirts down to their ankles), showed my parents and myself around the hospital. We passed through the corridors with orange, blue, and yellow lines running down the walls. A heavy door closed behind us like a tetherball being punched. She explained matter-of-factly that the door

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# Trapped

By Kimberley Warsett

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locks automatically. Locks? What did she think I would do? I may have not been an angel, but why lock me in?

This was the first time I realized that I'd need to keep my soul jailed. That it was not good enough to run freely. That I would have to shut myself up, when at times I would be more inclined to talk.

After showing us around, she suggested I eat lunch with the other kids. I looked at the table and did not want to sit there. Everyone was intensely turned inward and quiet. There was the girl who the staff was forcing to eat a grape. She refused. She had "anorexia nervosa" and wanted to be left alone. There was a skinny boy picking at his food.

I did not know anyone and wished I could just sit with my parents while they ate at another table in the cafeteria. But I followed the rules.

As the weeks went by, I realized how exquisite the other clients were. An eight-year-old was on the unit. She would have "temper tantrums" and be placed in the quiet room where she'd continue to scream. Screaming for your rights is not proper form, we learned. But she could give advice to the rest of us, better than anyone three

times her age.

There was the guy that threw 2 liter soda bottles down the stairs of his house at his parents when he was upset. He danced in the community room with such rhythm, that he brought a party feeling to the hospital.

We were taught the rules of life. We sat in a circle with the long-skirted women and discussed what we should say to others about where we've been when we get home. It's best not to tell everyone the whole truth seemed to be the bottom line. Our life stories could make us pariahs, they almost suggested.

So we learned to hide. To hide our "illness," our voice of empowerment, our own history.

I left the hospital no longer manic, drugged and trembling so much that I had to teach myself again how to write, and knowing that I had more important things to do in life than walk around the green with doctors and listen to others tell me how to contextualize my mania. The hospital time was the start of changing me from an open no-secrets person, to a person with a world locked-up inside that I can't easily share. I learned that a standard definition of sanity is right

to get through life, and if I don't live up to that-well the hospital's still there for me.

## Looking for Alternatives

By Marina Colonas

Marina's Story

When I was first joined this community of people with lived experience..... I felt 'less than' because I had never been hospitalized. I was embarrassed because I thought that my experience with mental health was not 'enough' and I didn't belong.

It took me a long time to realize that what I went through was indeed valid and I did belong and chose to belong.

I was feeling big waves of despair, all I saw was darkness, sadness, a void, non stop crying, unable to express what I felt, there was no sun inside or out, instead of sleeping and eating a lot I switched to not sleeping or wanting to eat much. Nothing was predictable, nothing was familiar. I was scared. I was terrified.

I went to the city hospital hoping for a place to sleep and eat. I wanted to be able to come and go and not be locked in or forced to attend meetings. They said that was impossible and that I would have to agree to be locked up. I refused. Now, I know I was looking for a respite place. A place to heal on my terms, no locked ward.

My meds Doctor at that

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time was a practicing Buddhist and a 12 stepper. I had finally admitted that I didn't feel right. It was the first time I had tried psychiatric ("legal") medications. After 9 months of trying different combinations and doses of varying medication that were not working it was suggested I do electric shock therapy. Everything I had read about ECT scared me and I refused to do it.

My sister Rene began to help me. Her part of the story follows. We agreed that I would go to a partial day program. In addition, I was to sign a 'safety contract', stating that I would not harm myself. I set a schedule for myself that I would follow when I left the daily partial program.

Other 'breakdowns' ( I now consider these breakthroughs) kept happening. I entered three other partial programs. Because my sister was involved in the de-institutional of state hospitals in the 1980s?, she knew that hospitals would not help me and may possibly make my condition worse. She helped me find another partial, HRI, a place that she helped co found.

My last "breakdown" was in 1999. My sister suggested I go with her to meetings about a new project in western MA. That was how I found WRAP ( Wellness Recovery Action Plan). Slowly I learned about it and began to heal, was trained as a WRAP Facilitator, and began teaching. The WRAP became and is how I live my life today. I have not had any issues? That I can't handle since then. I am and continue to heal.

I know how lucky I am not to have entered hospitals and thank my sister for that. Two years ago I visited Rose House in New York, a peer run respite program. That was the kind of program I was originally looking for before I started my quest for help.

#### Rene's Story

My memories of this time, "the time of Marina's pain", is somewhat different than Marina's when I consider events but not in the feelings. Witnessing someone I loved for so long go through the darkness left me feeling helpless, powerless, my grief knew no bounds. It awoke the fire-breathing dragons of the past and enraged me. I could not protect her from harm as a child and, now, as an adult I could not hold her pain, shield her from the horrific past shadowing the difficult present.

In my early work in the area of mental health, I had mighty mentors who shaped my thinking on the experience of madness. From Judy Chamberlain and Rae Unzicker I learned the wisdom gleaned as a result of surviving the psychiatric system and the necessity of keeping our brothers and sisters out of institutions.

From my colleagues David Specht, Marylou Sullivan and Michael Kendrick and Debi Reidy, I learned how best to use my position and power to support the voices of people with psychiatric diagnoses. On a personal level, my own journey as a survivor of violence, a woman in sub-

stance abuse recovery, and a person whose psych labels continually changed over the years, including the kiss of death diagnosis – borderline.

After many conversations, I asked Marina if I could talk to her therapist in my role as advocate. From there my role as advocate, supporter and sister became more distinct and clear between Marina and myself.

# GET YOUR VOICE HEARD!

This may be the peer community's opportunity to push the Department of Mental Health (DMH) to truly follow their **Community First** Plan and achieve the vision of creating flexible, recovery-based and person-centered services supporting consumer choice. Massachusetts' terrible fiscal situation is accelerating DMH's consideration of whether scarce dollars should be spent on very expensive institutions or on community-based services.

The Executive Office of Health & Human Services has created a Department of Mental Health Inpatient Study Commission which will make recommendations on how big the DMH inpatient system should be. This 15 member commission, with only 2 consumer representatives, will hold five public hearings throughout the state in early June. This is our only chance to educate the commission on trauma-informed care, peer support and what really does help us recover.

## COME OUT & SPEAK AT THE INPATIENT STUDY COMMISSION!

**THIS IS YOUR ONLY CHANCE TO LET DECISION-MAKERS KNOW  
WHAT YOU THINK ABOUT STATE MENTAL HOSPITALS!**

### Tentative Hearing Dates:

**Wed. June 3; 2-4 PM—Boston**

**Thurs. June 4; 4-6 PM—Central MA** (*probably Worcester*)

**Tues. June 9; 4-6 PM—Southeast MA** (*probably Brockton*)

**Wed. June 10; 4:30-6:30 PM—Western MA** (*probably Holyoke*)

**Fri. June 12; 2-4 PM—Northeast MA** (*probably Lawrence/Lowell*)

Locations for the hearings have not yet been announced. To confirm the date, time & location of the hearing in your area, go to [www.mass.gov/eohhs](http://www.mass.gov/eohhs) & click the link for the Inpatient Study Commission (submit written comments at this link by 6/12) or call the Transformation Center at (617) 442-4111 or toll-free at (877) 769-7693 .

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